

IN THE  
**Supreme Court of the United States**  
OCTOBER TERM, 1996

Supreme Court, U.S.

FILED

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STATE OF WASHINGTON, et al.,

*Petitioners,*

vs.

HAROLD D. GLUCKSBERG, M.D., et al.,

*Respondents.*

DENNIS C. VACCO, ATTORNEY GENERAL OF THE STATE  
OF NEW YORK, et al.,

*Petitioners,*

vs.

TIMOTHY E. QUILL, M.D., et al.,

*Respondents.*

ON WRITS OF CERTIORARI  
TO THE UNITED STATES COURT OF APPEALS  
FOR THE SECOND AND NINTH CIRCUITS

**BRIEF OF THE WASHINGTON STATE  
PSYCHOLOGICAL ASSOCIATION, THE AMERICAN  
COUNSELING ASSOCIATION, THE ASSOCIATION  
FOR GAY, LESBIAN AND BISEXUAL ISSUES IN  
COUNSELING, AND A COALITION OF MENTAL  
HEALTH PROFESSIONALS AS AMICI CURIAE  
IN SUPPORT OF RESPONDENT**

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## **QUESTION PRESENTED**

Whether a State may prohibit physicians, completely and under any set of circumstances, from providing mentally competent, terminally ill adults with the means medically necessary to choose the manner and timing of their death.

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IN THE SUPREME COURT OF THE UNITED STATES

OCTOBER TERM, 1996

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No. 96-110

STATE OF WASHINGTON, et al., *Petitioners*,

v.

HAROLD GLUCKSBERG, M.D., et al., *Respondents*.

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No. 95-1858

DENNIS C. VACCO, ATTORNEY GENERAL OF THE  
STATE OF NEW YORK, et al., *Petitioners*,

v.

TIMOTHY E. QUILL, et al., *Respondents*.

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**BRIEF FOR THE WASHINGTON STATE  
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PROFESSIONALS AS AMICI CURIAE SUPPORTING  
RESPONDENT**

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## INTEREST OF THE AMICI<sup>1</sup>

Any consideration of the question before the Court in this case must involve the related issues of (i) whether a mentally competent adult patient would ever freely choose to hasten death, and (ii) whether it is possible to ascertain that a particular patient is mentally competent, adequately advised, and has freely made such an irrevocable choice. The amici are mental health professionals whose training and experience qualify them to provide the Court with insight on these important questions.<sup>2</sup>

The Washington State Psychological Association ("WSPA") is a non-profit professional association of approximately 900 doctoral level psychologists, and other related mental health practitioners. The WSPA's mission is to support, promote and advance the science and practice of psychology in the public interest. Many WSPA members work in areas directly affected by the issues raised by physician-assisted suicide, and confront the problems faced by terminally ill patients and their families on a regular basis. WSPA members routinely assess the mental capacity of patients, including those who are terminally ill and those contemplating suicide. By reason of the skills, training and experience of its members, WSPA believes it can provide meaningful insight into the mental capacity of terminally ill patients and into the diagnostic and evaluative resources available to verify such capacity. While the existence of a constitutional right to die is a legal question beyond the

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<sup>1</sup> This Brief is being filed with the written consent of all parties in accordance with Sup. Ct. R. 37(2)(a).

<sup>2</sup> Mental health professionals include psychiatrists, psychologists, social workers, professional counselors and marriage and family therapists.

special expertise of WSPA, WSPA hopes to demonstrate that evaluative processes do exist for reliably assessing mental capacity, even for patients who are terminally ill, and even for patients who may contemplate suicide.

The American Counseling Association ("ACA") is the largest non-profit organization of professional counselors in the United States, with approximately fifty-five thousand members. ACA is an educational, scientific, and professional organization whose members are dedicated to the enhancement of human development throughout the life span, and who work to support and enhance the worth, dignity, potential and uniqueness of each individual. Indeed, the ACA's Code of Ethics and Standards of Practice states that "The primary responsibility of counselors is to respect the dignity and to promote the welfare of clients." Many of ACA's members provide mental health services, including psychotherapy and psychological assessments. Professional counselors serve in private practice, community mental health centers, mental health agencies, schools, universities, hospitals, rehabilitation facilities, business, industry, correctional institutions and religious organizations. ACA's members are trained in the diagnosis, etiology, and treatment of mental and emotional disorders, including depression. Given the counseling profession's largely unique focus on human development, and on individual self-determination and self-actualization, ACA feels it imperative to express its position regarding the ability of terminally ill adults to choose the manner and hasten the timing of their death.

The Association for Gay, Lesbian & Bisexual Issues in Counseling ("AGLBIC") is an association of gay and non-gay professional counselors seeking to promote greater understanding and insight toward counseling gay, lesbian and bisexual clients. AGLBIC offers professional training for all counselors interested in developing clinical skills that will

enable them to be more effective. AGLBIC's interest in these cases stems from its members' experience with gay, lesbian, and bisexual persons with HIV disease.

The Coalition of Mental Health Professionals Supporting Individual Self-Determination in Decisions to Hasten Death is an ad hoc group of academics, private practitioners, administrators and consultants. These individuals have training and experience in the mental health professions which makes it appropriate for them to offer their views on the possibility of free and rational choice in the context relevant to this case. All Coalition members have extensive experience providing psychotherapy, often to persons who are terminally ill, and/or strong records of research and writing on depression, grief, suicide, psychotherapy, personality disorders, and substance abuse. A list of Coalition members is attached to this brief as Appendix A.

## SUMMARY OF ARGUMENT

The decisions of the courts of appeals in these cases limit their holdings to a narrow set of circumstances: cases involving mentally competent, terminally ill adults who have made, or wish to have the option to make, the choice to select the manner and hasten the time of an otherwise quickly and inevitably approaching death. Implementation of either decision therefore depends on the ability to assess whether a terminally ill patient is mentally competent, and whether a particular decision to seek assistance in dying is rational and voluntary. These central issues of the competence, rationality, and voluntariness of end-of-life decisions are ones with respect to which many mental health professionals have special training and experience.

Two central values for mental health professionals are the intertwined principles of client autonomy and self-determination. Mental health professionals do not promote



any particular resolution of the terminal-care issues that may arise near the end of a client's life. Rather, in the context of end-of-life decisions, clients are helped by providing them with the means to make informed choices.

In determining legal competence, courts have inevitably relied on the training, experience, and judgment of qualified mental health professionals to assess an individual's capacity to make reasoned decisions. In the context relevant to these cases, there is no dispute that States may appropriately set high standards for making such assessments. Under existing or suggested standards, an evaluator would focus, for example, on a patient's ability to make a coherent assessment of costs and benefits and to draw conclusions that are logically consistent with his or her own values, rather than on the particular outcome of the patient's deliberation. Once appropriate standards have been set, mental health professionals who have the requisite training, experience, and direct contact with an individual patient will be in a position to assess whether the patient has the capacity to make a reasoned end-of-life decision.

There should be no dispute that, before allowing a physician to assist a terminally ill patient to hasten death, a State may also constitutionally require some particularized assessment of the patient's end-of-life decision. Although some have argued that *any* decision to hasten the end of one's life must be either irrational or the product of mental illness, that argument is merely conclusory. Evaluation of particular decisions must instead focus first and primarily on the deliberative process involved, not on the decision ultimately made. Similarly, neither research nor experience supports the assertion that decisions to hasten death are so highly correlated with mental illness as to justify a prophylactic rule banning all physician assistance in dying. Rather, research indicating that terminal illness, particularly

if accompanied by intractable pain or other special circumstances, presents a special case for rational suicide is reinforced by studies showing that a significant proportion of mental health professionals believe that hastening death can be a reasonable choice. Under proper circumstances, a choice to control the manner and hasten the time of one's own death is neither inherently irrational nor indicative of mental illness.

Mental health professionals who work with terminally ill patients are as concerned as others that decisions to hasten death not be impulsive or ambivalent, and that they be made free from any coercion or undue influence. Such dangers may largely be avoided through appropriate state regulation, including mandatory waiting periods and the involvement of mental health professionals in evaluation and counseling. With a strong commitment to patient autonomy as a guiding principle, mental health professionals are uniquely suited to serve as counselors and advocates for terminally ill patients in the face of any improper pressure. Moreover, appropriate safeguards may be put in place without denying patients who are in a position to make free, informed, and intelligent end-of-life decisions the opportunity to do so.

Frank discussion of end-of-life issues among terminally ill patients, their treating physicians, and appropriate mental health professionals would necessarily raise the issues of capacity, rationality, and voluntariness discussed in this brief. The process of evaluation and counseling that should accompany any end-of-life decision will often lead patients to choose some option other than assisted suicide — even if the patient actively considers that course as one possibility. The cases before the Court involve what is presently, and is likely to remain, a minority of patients who reach a carefully considered decision to hasten the end of life, even after a thorough exploration of the alternatives. Nonetheless, various

considerations suggest that protection of the public would be enhanced, not diminished, by bringing physician assistance in dying into the open and allowing for comprehensive legal regulation.

## ARGUMENT

### I. RECOGNITION AND IMPLEMENTATION OF THE CONSTITUTIONAL RIGHT AT ISSUE IN THESE CASES DEPENDS ON THE ABILITY TO ASSESS WHETHER A TERMINALLY ILL PATIENT IS MENTALLY COMPETENT, AND WHETHER SUCH A PATIENT IS ACTING RATIONALLY AND VOLUNTARILY WHEN HE OR SHE SEEKS ASSISTANCE IN CHOOSING THE TIME AND MANNER OF DEATH.

This case presents the narrow but important question whether a State may constitutionally prohibit physicians, under any set of circumstances, from providing mentally competent, terminally ill adults with the means medically necessary to choose the manner and hasten the timing of their death. In the opinion below in No. 96-106, the Ninth Circuit recognized "a constitutionally protected liberty interest in determining the time and manner of one's own death." *Compassion in Dying et al. v. State of Washington et al.* 79 F.3d 790, 793 (9th Cir. 1996). The court then held that, in the particular context of a competent, terminally ill patient whose physician is willing to prescribe appropriate medication, that interest outweighs even the State's substantial general interest in preventing suicide. In that context, the court held, "the state has wide power to regulate, but it may not ban" willing physicians from providing medical assistance to a competent patient who chooses to hasten the already fast-approaching end of life.

In No. 95-1858, the Second Circuit reached a similar result through different reasoning. That court first determined that New York law recognizes and respects a terminally ill patient's right to refuse or order the discontinuance of life-sustaining treatment, including artificial nutrition and hydration. *Quill et al. v. Vacco et al.* 80 F.3d 716, 727-28 (2d Cir. 1996). The court then concluded that the State treats other competent, terminally ill patients unequally, by prohibiting even a willing physician from prescribing appropriate drugs if and when such a patient wishes to hasten the moment of his or her own impending death. *Id.* at 729. In the limited context of mentally competent, terminally ill patients, the court discerned no rational relationship between that inequality of treatment and any legitimate state interest. *Id.* at 730-31. The court therefore struck down the State's criminal prohibition on assisting suicide, as applied to "prohibit a physician from prescribing medications to be self-administered by a mentally competent, terminally ill person in the final stages of his terminal illness." *Id.*

Although the opinions below rest on different legal theories, both are notable for the care they take to limit their holdings to a narrow set of factual circumstances: cases involving mentally competent, terminally ill adults who have made, or wish to have the option to make, the choice to select the manner and hasten the time of a quickly and inevitably approaching death. Whatever the proper legal analysis, both decisions therefore depend on two important factual propositions: that it is generally possible for a competent person to make a reasoned decision to hasten the end of his or her own life, and that it is possible in any given case to assess the decision-making capacity of an individual patient and the soundness of his or her decision-making process.



Moreover, whether the right in question is guaranteed directly by the Constitution, or as a matter of parity with rights already afforded by a State to individuals who wish to terminate life-sustaining care, both decisions seek to protect a sphere of personal autonomy — specifically, an individual's right to choose the time and manner of ending the suffering caused by a terminal illness. That protection is only sensible or desirable, however, if the choice protected is in fact an autonomous decision made by the individual patient. Conversely, the State's interest in regulating, or even prohibiting, end-of-life decisions of this type increases to the extent that there is any uncertainty about whether a particular patient's choice is truly voluntary.

These central issues concerning the competence, rationality, and voluntariness of end-of-life decisions are ones with respect to which many mental health professionals have special training and experience. Moreover, the mental health professions have long grappled with the ethical issues that arise in this context. The amici offer the following observations to the Court in the hope that they will be helpful in informing the Court's decision on the important question presented by these cases.

## **II. MENTAL HEALTH PROFESSIONALS ARE GUIDED IN THEIR APPROACH TO END-OF-LIFE ISSUES BY ETHICAL PRINCIPLES THAT INCLUDE PATIENT AUTONOMY AND SELF-DETERMINATION, BALANCED BY LEGAL NORMS AND CONCERN FOR PUBLIC WELFARE.**

The analysis provided in this brief is grounded in underlying ethical principles that guide the work of mental health professionals. Mental health professionals accord appropriate respect to individuals' fundamental interests in

privacy, self-determination, and autonomy, while remaining mindful that those interests may conflict with legal and other obligations. When conflicts occur, professionals attempt to resolve them and to perform their roles in a responsible fashion that avoids or minimizes harm. They are aware of their professional and scientific responsibilities to the communities and society in which they work and live. Professionals apply and make public their knowledge of mental health in order to contribute to human welfare. They work to identify and mitigate the causes of human suffering.

Two central values for mental health professionals are the intertwined principles of client autonomy and self-determination. In the context of end-of-life decisions, clients are helped by providing the means for them to make informed choices. Mental health professionals do not promote any particular resolution of the terminal-care or other issues that may arise near the end of a patient's life. Rather, mental health workers who have appropriate training and immediate involvement with those suffering from terminal illnesses can help patients to explore, ameliorate, cope with, or solve problems that interfere with the patient's own control over his or her life and death.

Professionals can, for example, help patients to address issues such as pain, depression, dignity, tranquility, financial concerns, and the effectiveness or futility of available medical treatments. In addition, they can assist the patient to communicate with other health care providers, family members, social service providers, or others concerning the patient's needs, concerns and preferences, to help ensure that the patient receives necessary support and that the treatment provided comports with the patient's wishes. Finally, professionals can promote and monitor appropriate involvement by significant others in a patient's end-of-life decisions, and they can counsel both patients and survivors

in the inevitable process of grieving. *See generally, e.g.,* National Association of Social Workers, *Client Self-Determination in End-of-Life Decisions*, in *Social Work Speaks: NASW Policy Statements 60* (3d ed. 1994) "NASW Statement", (reprinted as Appendix B hereto). In all these roles, mental health professionals seek to advance the ideals of client autonomy and self-determination, subject to the requirements of the law and concern for the general public welfare.

**III. IT IS POSSIBLE TO ASSESS WHETHER OR NOT A TERMINALLY ILL PATIENT WHO HAS REQUESTED ASSISTANCE IN HASTENING DEATH IS MENTALLY COMPETENT AND HAS MADE A REASONED, INFORMED, AND VOLUNTARY DECISION TO SEEK SUCH ASSISTANCE.**

**A. Assessing Capacity to Make Reasoned Decisions**

Both decisions below begin with the assumption that a terminally ill patient who seeks assistance in choosing the means and time of his or her own death must be "mentally competent" to make that final decision. Similar situations involving the assessment of mental competence or capacity arise in a variety of legal contexts, from competence to stand trial to competence to make a valid will. *See, e.g., Cooper v. Oklahoma*, 116 S. Ct. 1373 (1996) (competence to stand trial); *Addington v. Texas*, 441 U.S. 418 (1979) (involuntary civil commitment); Cal. Prob. Code § 812 (West Supp. 1996) (specifying criteria to be used in determining legal incapacity to perform various acts, including "to contract, to make a conveyance, to marry, to make medical decisions, to vote, or to execute wills or trusts."). Competence is a legal

question, which, when disputed, must ultimately be resolved by the courts. In deciding such issues, however, courts have inevitably relied on the training, experience, and expert judgment of qualified mental health professionals to assess a given individual's capacity to make reasoned decisions. *See, e.g., Medina v. California*, 505 U.S. 437, 450 (1992); *see also id.* at 465 (Blackmun, J., dissenting).

Particular legal standards of competence vary depending on the rights and interests at stake in a given context. *See, e.g., Cooper*, 116 S. Ct. at 1383-1384 (contrasting standards for involuntary commitment and for competence to stand trial). In the context of patients' end-of-life decisions, there is no dispute that the standards for assessing decision-making capacity and legal competence may appropriately be set high. *Cf. Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 282-284 (1990); *Addington*, 441 U.S. at 423 ("The function of a standard of proof . . . is to 'instruct the factfinder concerning the degree of confidence our society thinks he should have in the correctness of factual conclusions for a particular type of adjudication.'"). While each State could establish its own standards and procedures for such cases, the mental health literature suggests that an appropriate standard would require that a terminally ill patient be able to:

- (a) understand and remember information relevant to an end-of-life decision;
- (b) appreciate the consequences of the decision;
- (c) indicate a clearly held and consistent underlying set of values that provide some guidance in making the decision; and
- (d) communicate the decision and explain the process used for making it.



See J. Werth, *Rational Suicide? Implications for Mental Health Professionals* 94 (1996).<sup>3</sup> A strict standard might also require that

"once understanding [of the information relevant to an end-of-life decision] has been attained, the patient's rational manipulation of information [must take] place in the context of the patient's appreciation of the nature of his situation."

Appelbaum and Roth, *Competency to Consent to Research*, 39 Archives Gen. Psychiatry 951, 954 (1982).

Under this type of standard, a mental health professional evaluating decision-making capacity would examine a patient's "chain of reasoning," and would seek to determine whether the patient can "indicate the major factors in his decisions and the importance assigned to them." Appelbaum and Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 New Eng. J. Med. 1635, 1636 (1988). The evaluation would focus on the patient's ability to make a coherent assessment of costs and benefits, and to draw conclusions that are logically consistent with his or her own values or other stated premises for the decision, rather than on the outcome of the patient's deliberation. See also Annas and Densberger, *Competence to Refuse Medical Treatment*:

<sup>3</sup> See also, e.g., Drane, *The Many Faces Of Competency*, 15 Hastings Center Report No. 2, 17, 19 (1985); Freedman, *Competence, Marginal and Otherwise: Concepts and Ethics*, 4 Int'l J.L. and Psychiatry 53, 59-60 (1981); Roth et al., *Tests Of Competency To Consent To Treatment*, 134 Am. J. Psychiatry 279, 280-282 (1984); Tepper and Elwork, *Competence To Consent To Treatment As A Psycholegal Construct*, 8 Law and Human Behavior 205.

*Autonomy vs. Paternalism*, 15 U. Tol. L. Rev. 561, 568 (1984).<sup>4</sup>

Once an appropriate standard has been set, mental health professionals who have the requisite training, experience, and direct contact with an individual patient will be in a position to assess, in the first instance, whether a patient has the capacity to make a reasoned end-of-life decision.<sup>5</sup> Many

<sup>4</sup> Compare Cal. Prob. Code § 813 (West Supp. 1996):

A person has the capacity to give informed consent to a proposed medical treatment if the person is able to do all of the following:

(a) Respond knowingly and intelligently to queries about that medical treatment.

(b) Participate in that treatment decision by means of a rational thought process.

(c) Understand all of the following items of minimum basic medical treatment information with respect to that treatment:

(1) The nature and seriousness of the illness, disorder, or defect that the person has.

(2) The nature of the medical treatment that is being recommended by the person's health care providers.

(3) The probable degree and duration of any benefits and risks of any medical intervention that is being recommended by the person's health care providers, and the consequences of lack of treatment.

(4) The nature, risks, and benefits of any reasonable alternatives.

See also Calif. Prob. Code § 1881 (West Supp. 1996) (standards of informed consent for conservatees).

<sup>5</sup> This Court has commented that "the subtleties and nuances of psychiatric diagnosis render certainties virtually beyond reach in most situations." *Medina*, 505 U.S. at 451, quoting *Addington*, 441 U.S. at 430; see also *Cooper*, 116 S. Ct. at 1382. In this context as in other areas of law (or medicine), however, the impossibility of certainty does not obviate the need to decide. *Id.* at 1382-83. The nature of end-of-life decisions would certainly justify a State in adopting a legal standard (continued...)



mental health professionals have extensive experience in making both formal written evaluations and ongoing, informal assessments of decision-making capacity and rationality during the course of psychotherapy, counseling, or psychiatric consultation in medical settings. Indeed, professional evaluation occurs continuously during therapy and within the context of hospital or outpatient consultations. Is the client sensing, perceiving and comprehending information regarding his or her situation accurately? Is the client realistically formulating and utilizing this information? Are the client's perceptions being unduly influenced by mental disorders, prescribed medications, substance abuse, or external social or economic pressures? Overall, is the client fully informed and rational? General criteria exist, and specific criteria may be adopted, for making such evaluations in the case of terminally ill patients who seek physician assistance in controlling the manner and timing of their deaths. See, e.g., J. Werth, *supra*, at 94-95. Specification and refinement of those criteria, and their application in particular instances, are well within the competence of the mental health profession.

#### B. Assessing the Rationality of a Decision

Even if a person generally has the capacity to make reasoned judgments, he or she may make particular choices that are unduly influenced by factors not associated with rational decision-making, such as coercion, inadequate treatment, prescribed medications, drugs, alcohol, or mental disorders. There should be no dispute that, before allowing

<sup>3</sup>(...continued)

under which close cases are resolved in favor of preserving the medical status quo. See *Cruzan*, 497 U.S. at 283. But the inevitability of close cases cannot, by itself, justify imposing a flat prohibition that will apply even in cases where the evidence of mental capacity is clear.

a physician to assist a terminally ill patient in selecting or hastening the moment of death, a State may constitutionally require not only an assessment of general mental capacity, but some particularized assessment of the patient's end-of-life decision. If allowed to address the issue openly, without fear of legal or ethical repercussions, mental health professionals can provide such assessments. See, e.g., Holtby, *Social Work, Suicide, and Self-Deliverance*, 1 National Social Work AIDS Network Readings and Writings No. 3, 30 (1996); Quill et al., *Proposed Clinical Criteria for Physician-Assisted Suicide*, 327 New Eng. J. Med. 1380, 1381-82 (1992); J. Werth, *supra*, at 55-80. Moreover, the involvement of mental health professionals and the use of open discussion and evaluation can facilitate the sort of full consideration that leads to an informed and deliberate decision, whatever it may ultimately be.

#### 1. "Inherent irrationality"

It may be argued that any decision to hasten the end of life must be either irrational or a product of mental illness. See, e.g., Brief for the American Suicide Foundation, Amicus Curiae, Supporting Reversal (Case No. 96-110) 5-11, 13 ("Am. Cur. Br. for the ASF"). That argument, however, assumes its conclusion. For example, one of the guiding principles for mental health professionals is client autonomy — allowing and encouraging clients to take control of their lives and assume responsibility for their decisions. In the argument for the inherent irrationality of suicide, however, a patient who chooses to forgo medical treatment is said to make only "a judgment about how to live before one dies," *id.* at 13, while a patient who desires to exercise essentially the same control over the final portion of his or her life by choosing the time and manner of death is characterized as "afflicted" by a "rigidity" that reflects

"impaired thought processes and irrationality," *id.* at 8. Similarly, the right to forgo treatment is treated as "rooted in our abhorrence of the violence inherent in forcing medical interventions on unwilling, competent adults," but the essentially identical choice to avoid the same "intense burdens, such as pain, bodily invasion, and the emotional suffering that can accompany . . . a course of treatment" by an active hastening of death is dismissed as necessarily a product of "mental impairment." *Id.* at 13-14. Thus, the argument succeeds only because it *defines* a request for active assistance in dying as "irrational."

As with determinations of competency and decision-making capacity, evaluation of a particular end-of-life decision must instead focus first and primarily on the deliberative process involved, not on the decision ultimately made. "If the reasoning process flows logically from its starting premises, though the result might be rejected by most people (*e.g.*, a person refusing potentially life-saving medical treatment), we cannot say that rational manipulation is impaired." P. Appelbaum and T. Gutheil, *Clinical Handbook of Psychiatry and the Law* 223 (1991). A patient who is fully informed, realistic, stable, and not mentally impaired — as determined, for example, by professional observation of the patient's behavior and ability to interact and communicate — may make a knowing and intelligent decision to decline (or accept) treatment, or to request (or decide against) assistance in dying. That is true even if the decision is based in part on "irrational" or super-rational factors, such as religious beliefs or other transcendent moral values.

To be sure, assessing the soundness of a terminally ill patient's decision to hasten death will sometimes present special challenges. In cases of terminal illness, the criteria for measuring the existence of mental disturbance are

particularly likely to be confounded by the effects of the physical disease itself. For similar reasons, it may be difficult to differentiate between normal grief — a reaction to actual or prospective loss — and clinical depression. See R. Neils, *Dying Well Network: Death with Dignity FAQs (Frequently Asked Questions)* § 4.18 (a copy of which has been lodged with the Clerk). Indeed, of the nine standard criteria for diagnosing a "major depressive episode," several may be present simply because of physical illness, and six may appear in a terminally ill patient simply because of natural grieving over the functional impairment caused by serious illness and over the impending loss of his or her life.<sup>6</sup>

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<sup>6</sup> The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* lists nine criteria for identifying a Major Depressive Episode. A grievously ill person who is not clinically depressed may meet criteria 2, 3, 4, 5, 6, and 9:

- 1) Depressed mood most of the day, nearly every day, as indicated by either subjective report (*e.g.*, feels sad or empty) or observation made by others (*e.g.*, appears tearful);
  - 2) Markedly diminished interest or pleasure in all, or almost all activities most of the day, nearly every day (as indicated by either subjective account or observation made by others);
  - 3) Significant weight loss when not dieting or weight gain (*e.g.*, a change of more than 15% of body weight in a month) or decrease or increase in appetite nearly every day;
  - 4) Insomnia or hypersomnia nearly every day;
  - 5) Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down);
  - 6) Fatigue or loss of energy nearly every day;
  - 7) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick);
  - 8) Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as
- (continued...)



With training and experience, however, a professional can distinguish clinical depression from physical illness or grief, for example on the basis of a patient's feelings of worthlessness or excessive guilt. An individual's sense of self-worth is typically unaffected by physical illness or grief, but significantly impaired in cases of clinical depression. Thus, a depressed patient might inappropriately request suicide precisely because of feelings of worthlessness and guilt. For a terminally ill patient, on the other hand, being able to assert some modicum of control over the course of an inevitable final illness, by choosing at least the time and manner of death, may be a final act of will that reflects — indeed, affirms — self-esteem and individual dignity. The differences between these situations may sometimes be subtle, but they are real, and mental health professionals who work with the terminally ill are qualified to assess them.

An assessment of any particular end-of-life decision should take into account not only the patient's ability to reason coherently, but also the information that the patient has considered in reaching his or her decision. Even if a patient receives fully adequate medical care, his or her physicians may be focused on the details of particular medical problems, rather than on the patient's entire circumstances. The patient will also inevitably be under considerable mental and physical stress. Mental health professionals can provide objective information and counseling about the patient's overall situation, including

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<sup>6</sup>(...continued)

observed by others); and/or

9) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicidal attempt or a specific plan for committing suicide.

American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders* 327 (4th ed. 1994).

alternatives of which neither the patient nor his or her attending physicians may be aware. See N. Peruzzi et al., *Ethics and Behavior* 8-13 (forthcoming 1997); NASW *Statement, supra*, at 60. They may, for example, be able to provide information about alternatives such as hospice programs, independent or assisted living arrangements, and potential sources of financial or other assistance. They can act as liaisons or patient advocates in coordinating comprehensive care. They are also well positioned to assess the patient's overall psychological state, and to recognize signs of misunderstanding, clinical depression, or other factors which suggest that the patient's decision-making ability may be compromised. They can offer the patient a sympathetic sounding-board, identify the factors that appear to be driving an end-of-life decision, and offer either confirmation that the facts are as the patient perceives them to be, or new or different information that may change or help to inform the patient's decision.

## 2. *Correlation with mental illness*

Even if some decisions to request assistance in dying may be fully informed and intelligently made, it may be argued that a decision to hasten death is so highly correlated with mental illness that the State is justified in enacting a prophylactic rule banning all physician assistance in dying. Cf. Black and Winokur, *Suicide and Psychiatric Diagnosis, in Suicide Over The Life Cycle: Risk Factors, Assessment, and Treatment of Suicidal Patients* 135, 139 (S. Blumenthal and D. Kupfer eds., 1990) ("few suicides occurred in persons judged not mentally ill, suggesting that the 'rational' suicide is uncommon."). In fact, the correlation between all suicide

and mental illness may be overstated.<sup>7</sup> Even if the

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<sup>7</sup> Research indicating that the majority of individuals who commit suicide have one or more mental illnesses may be misleading. Even accepting the data as reported, these studies also show that from 3%-12% of people who have killed themselves had no mental illness. Black and Winokur, *supra*, at 139; Clark and Horton-Deutsch, *Assessment in Absentia: The Value of the Psychological Autopsy Method for Studying Antecedents of Suicide and Predicting Future Suicides*, in *Assessment and Prediction of Suicide* 144, 148-49, 153-54 (R. Maris et al., eds., 1992). Other researchers report studies in which more than 25% of completed suicides did not have a mental disorder and could be considered rational. See R. Maris, *Pathways to Suicide: A Survey of Self-Destructive Behaviors* (1981); Meerloo, *The Multifarious Motivations for Suicide*, in *Suicide and Mass Suicide* 18, 25 (J. Meerloo ed. 1962); Patel, *Pathology of Suicide*, 13 *Medicine, Science, and the Law* 103, 106 (1973). After studying suicide notes, Tuckman, Kleiner, and Lavell stated that they "were impressed with the possibility that in a number of cases the suicide could have resulted from a conscious, 'rational' decision reached by weighing the pros and cons of continuing to live." Tuckman et al., *Emotional Content of Suicide Notes*, 116 *Am. J. Psychiatry* 59, 62 (1969). See also Shneidman et al., *The Suicide Prevention Center*, in *The Cry for Help* 6, 13 (N. Farberow and E. Shneidman eds., 1961) ("A large minority of suicides, usually older persons in physical pain, are logical and rational and not psychotic.")

Other studies suggest that the data linking suicide and mental illness may be oversimplified. Tanney noted that dramatic differences appeared when studies of the association between mental illness and suicide are broken down into general population surveys and hospital surveys. He reported that, on average, only 38% of completed suicides in the general population had a known history of mental disorder, while, on average, more than 80% of suicides in hospital-based surveys had a psychiatric disorder or history of care. Tanney, *Mental Disorders, Psychiatric Patients, and Suicide*, in *Assessment and Prediction of Suicide* 277, 283-84 (R. Maris et al. eds., 1992). Similarly, Temoche, Pugh, and MacMahon reported all the highest estimates (47%-94%) of the percentage of suicides who displayed prior evidence of mental illness come from studies done *after* the suicide occurred; in studies dependent

(continued...)

correlation holds for suicides in general, however, the argument for a prophylactic ban is not persuasive in the context of end-of-life decisions by terminally ill patients. In that context, physician-assisted "suicide" is far less akin to what is commonly termed suicide — typically a violent self-destructive act related to feelings of worthlessness — than it is to the thoughtful decision to decline life-sustaining treatment. The latter is a choice that upholds and affirms the dignity of a fully lived life, and one that many States, including New York and Washington, have already recognized as worthy of legal recognition. See, e.g., *Compassion in Dying*, 79 F.3d at 817-20; *Quill*, 80 F.3d at 727-28.

In fact, a number of researchers and clinicians have recognized that terminal illness, particularly if accompanied by intractable pain or other special circumstances, presents a special case for "rational" suicide. See, e.g., Siegel, *Rational Suicide: Considerations for the Clinician*, 54 *Psychiatric Quarterly* 77, 78 (1982) ("We need not argue the issue whether it is rational for an individual with painful terminal illness to refuse extraordinary life-saving measures or to more actively arrange to end his life. Most would agree it is rational."); Quill, *Physician-Assisted Death: Progress or Peril?*, 24 *Suicide and Life-Threatening Behavior* 315 (1994).<sup>8</sup> Moreover, research on suicide among the

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<sup>7</sup>(...continued)

upon objective criteria measured prior to the suicide, estimates of the correlation with mental illness were much lower (5%-22%). Temoche et al., *Suicide Rates Among Current and Former Mental Institution Patients*, 138 *J. Nervous and Mental Disease* 124 (1964).

<sup>8</sup> In one survey of 39 HIV-positive individuals, researchers concluded that more than two thirds had rationally contemplated suicide. Moreover, the desire to hasten death was not directly related to clinical depression

(continued...)



terminally ill must be interpreted with caution, because the cases likely to be studied are those that can be readily identified as "suicides," whereas other research indicates that many hastened deaths among terminally ill patients are never documented as such. S. Jamison, *Final Acts of Love: Families, Friends, and Assisted Dying* 5-6 (1995); R. Ogden, *Euthanasia, Assisted Suicide, and AIDS* 71-83 (1994). As a result, the research cited by opponents of hastened death must be viewed within an appropriately restrictive context, and it must be realized that it may not be possible to generalize the results. Several of the Coalition members listed in Appendix A have experience with literally hundreds of individuals who have died of terminal illnesses, and each could relate numerous stories of assisted deaths that were not reported as suicides. These professionals and the others who are members of the Coalition have chosen to join in this submission in part because their work has convinced them that the assertion that anyone, including terminally ill individuals, who wishes to hasten his or her own death must be depressed or otherwise mentally impaired is simply not borne out by either research or experience.

Recent research has found that a significant percentage of mental health professionals believe that hastening death can be a reasonable choice, and even have experience working with individuals who have made such decisions. In a national survey of a random sample of members of the American Psychological Association's Division of Psychotherapy, 81% of the respondents (with a 50% response rate) stated that they believed that an individual

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<sup>8</sup>(...continued)

as measured by the Beck Depression Inventory (the most widely accepted means of making swift diagnoses of depression). Jones and Dilley, *Rational Suicide and HIV Disease*, 8 Focus: A Guide to AIDS Research and Counseling 5 (July 1993).

could make a rational decision to control the time and manner of his or her own death. Werth and Liddle, *Psychotherapists' Attitudes Toward Suicide*, 31 *Psychotherapy: Theory, Research and Practice* 440 (1994). In another study, using a sample of psychologists who were members of the National Register of Health Care Providers in Psychology, 86% of the respondents (again with a 50% response rate) indicated that they believed in rational suicide. J. Werth, *supra*, at 47. Twenty percent of the participants in the latter study stated that they had worked with patients whose hastened deaths could be considered "rational" suicides in the sense described above. J. Werth, *supra*, at 53; see also Pope et al., *Ethics of Practice: The Beliefs and Behaviors of Psychologists as Therapists*, 42 *Am. Psychologist* 993, 1003 (1987).

Similar results have been found in surveys of psychiatrists. One study of physicians in Washington State found that of five categories of physicians, "psychiatrists were most supportive of" assisted suicide and euthanasia. Cohen et al., *Attitudes Toward Assisted Suicide and Euthanasia Among Physicians in Washington State*, 331 *New Eng. J. Med.* 89, 91-92 (1994) (especially graphs). A more recent report found that two-thirds of the respondents to a survey of Oregon psychiatrists (with a 77% response rate) "endorsed the view that a physician should be permitted, under some circumstances, to write a prescription for a medication whose sole purpose would be to allow a patient to end his or her life." Ganzini et al., *Attitudes of Oregon Psychiatrists Toward Physician-Assisted Suicide*, 153 *Am. J. Psychiatry* 1469, 1469 (1996).

For these reasons, we think it must be accepted that a decision by a terminally ill patient to hasten his or her own death may be carefully considered and fully rational — just as it may be ill informed or the product of impaired



reasoning. Given the opportunity, mental health professionals are capable of assessing the nature and quality of a patient's decision-making process, and therefore of helping to determine that any decision that is implemented is a product of the patient's knowing and intelligent choice.

The decisions below would permit, perhaps for the first time, a process of free and open discussion and consultation among patients, their physicians, and mental health professionals concerning all end-of-life options. Indeed, States could and should, in our view, require such consultation in any case in which the patient's ultimate choice is to select or hasten the moment of death.<sup>9</sup> The mental health professionals involved would be in a position to assess the accuracy of the patient's understanding of his or her medical condition, including the prognosis and treatment alternatives; to review the quality of the patient's deliberative process; and therefore to evaluate the psychological soundness of his or her final choice. Under proper circumstances, a choice to control the manner and

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<sup>9</sup> Oregon's "Death With Dignity Act," for example, adopted by the State's voters on November 6, 1994, requires a physician to refer a patient who requests aid in dying to counseling if the physician believes that the patient may be depressed or otherwise mentally compromised. 1995 Or. Laws Ch. 3 (I.M. 16). The counseling is to consist of consultation with a licensed psychiatrist or psychologist to determine whether the patient is suffering from a psychiatric or psychological disorder, or from depression causing impaired judgment. We note that other mental health professionals, including social workers and professional counselors, who have appropriate training or experience in working with the terminally ill would also be capable of performing such evaluations. See also Baron et al., *A Model State Act to Authorize and Regulate Physician-Assistance Suicide*, 33 Harv. J. on Legis. 1 (1996), which proposes a specific series of procedural requirements designed to prevent mistaken decisions. In particular, the model act requires a review of the patient's competence by suitably trained mental health professionals.

hasten the time of death is neither inherently irrational nor indicative of mental illness. Rather, such a choice may be the final expression of a terminally ill patient's individual autonomy.

### C. Assessing the Voluntariness of a Decision

The mental health professionals who work with terminally ill patients are as concerned as others that those patients who decide to hasten their own deaths make that decision free of any form of coercion or undue influence. They are equally concerned that a patient's choice may be merely impulsive, or that the patient may be so ambivalent that the simple passage of time is likely to change his or her mind. See, e.g., Am. Cur. Br. for the ASF 9-10. Although these dangers are real, they may largely be avoided by appropriate state regulation of the process by which such individuals request and receive physician assistance, including mandatory waiting periods and the involvement of mental health professionals in the sorts of evaluations and counseling described above.<sup>10</sup> This may be accomplished without, at the same time, denying patients who are in a position to make free, informed, and intelligent decisions the opportunity to do so. Indeed, the active and open involvement of mental health professionals in counseling terminally ill patients about end-of-life issues may well be the best guarantee that *all* such patients will have the

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<sup>10</sup> For example, Section 3 of the proposed *Model Act to Authorize and Regulate Physician-Assisted Suicide* also contains requirements that "the request must be competent, fully informed, voluntary, and enduring." See Baron, *supra* note 8, at 26. The proposed statute also mandates that a professional mental health care provider "evaluate the patient to determine that his or her decision is fully informed, free of undue influence, and not distorted by depression or any other form of mental illness." *Id.* at 18.

information and support necessary to make their own decisions, based on their own values, about the course of their own treatment and, ultimately, their own manner of dying.

Assessments of whether a particular decision reflects independent determination or improper outside influence, like assessments of capacity to make reasoned decisions, are as familiar to mental health professionals as they are to the law. Mental health professionals are used to working, in a wide variety of contexts, with individuals who may be susceptible to pressure, suggestion, or intimations of authority. With a strong commitment to patient autonomy as a guiding principle, mental health professionals are uniquely suited to serve as counselors and advocates for terminally ill patients to protect against any improper pressure on this most sensitive of decisions. That is true whether the pressure in question arises from physicians, hospital administrators, third-party payers or "managed care" controllers, family members, or other inappropriate or treatable sources such as clinical depression, feelings of worthlessness, transient mental disorders, the effects of alcohol or other drugs, financial concerns, inadequate palliative care, or a lack of social support.

Concerns with respect to voluntariness and the risk of coercion apply equally in the case of terminally ill individuals who refuse, or request the discontinuation of, life-sustaining treatment. Those choices have nonetheless been made available to patients, under whatever safeguards individual States have deemed appropriate. Indeed, it is possible that recognition of the right at issue in these cases, together with the sort of independent counseling requirements that the States might be expected to enact in this context, would increase the level of information and support available to *all* patients, and thereby actually

decrease the number who choose to end their own lives. In any event, open discussion of end-of-life issues, and active involvement by mental health professionals, would significantly enhance confidence that any patient who requests assistance in hastening the end of his or her life does so as a matter of free choice.<sup>11</sup>

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Recognition of a right to physician assistance in dying might well decrease those suicides that are of greatest legitimate concern to the State. Frank discussion of end-of-life issues between terminally ill patients, their treating physicians, and appropriate mental health professionals would necessarily raise the issues of capacity to make reasoned decisions, rationality, adequate information, exploration and availability of alternatives, and voluntariness discussed in this brief. Informed exploration of those issues might lead to the provision of appropriate treatment where all available methods have not been tried, and to the prevention of irrational and coerced deaths by those

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<sup>11</sup> With or without legal sanction, and with or without active or tacit professional assistance, some number of terminally ill patients already make their own decisions about exactly how and when to end their lives. One important effect of a decision affirming the judgments below might be to remedy an inequality akin to, but different from, that identified by the Second Circuit in *Quill*: the inequality between those patients who already have, whether through wealth, personal acquaintance, or mere physical ability, the de facto "right" to choose the time and manner of ending their battle with illness, and those whom disadvantage or disability consigns to live or die based solely on the medical and moral judgments of others. From the point of view of patient autonomy, surely it would be better to create a system under which some who have the power to die would receive the support or counseling that might convince them to live, while those who would truly choose to hasten their own ends would have the opportunity to do so without regard to fundamentally inconsequential criteria such as poverty or physical disability.



individuals who are not competent or rational (and whom the State has the greatest interest in protecting).

Similarly, because it is generally not legal to assist a patient to die, patients who wish to control their own deaths often reflect and act alone, without the benefit of counseling. They often believe that they must protect others by killing themselves in isolation, or earlier than they might otherwise choose, so they can be sure that they will still be able to carry out their own decision; or they may involve significant others, while feeling torn because doing so puts those individuals at risk both legally and emotionally. In either case, the results are often tragic. S. Jamison, *supra*, at 120-54; R. Ogden, *supra*, at 89-90. Drugs taken to hasten death, for instance, may not be properly absorbed, putting the patient at risk of further disability or prolonged suffering as a result of liver or kidney failure. Significant others may then be forced to become deeply involved. In desperation, they may even resort to violent measures, in which case the resulting post-traumatic stress compounds the tragedy. Holtby, *Social Work, Suicide, and Self Deliverance*, in 1 National Social Work AIDS Network Readings and Writings No. 3, 30 (1996). The availability of legal, regulated means for seeking assistance in dying, including the involvement of mental health professionals, would reduce these problems, and would allow professionals to deal openly with issues of emotional closure with a patient's family and helping the family to support the suffering individual. See, e.g., Lester, *Easing the Legacy of Suicide: Counselor Assisted Suicide*, in *Changes* (forthcoming 1997); J. Werth, *supra*, at 100. Protection of the public would thus be enhanced, not diminished, by bringing physician assistance in dying under the scrutiny of the law.

The process of discussion and counseling that should accompany any end-of-life decision often does lead patients

to choose some option other than assisted suicide — even if the patient actively considers that course as one possibility. In fact, anecdotal reports and some recent research suggest that giving some patients a credible option, or even the means, to hasten death if they decide to do so in the future may decrease the patient's desire to die immediately, and even enhance the quality of the patient's remaining life, thus reducing the risk that a patient will act impulsively or prematurely. See Back et al., *Physician-Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician Responses*, 275 JAMA 919, 922 (1996); Block and Billings, *supra*, at 2045; See M. Battin, *The Death Debate-Ethical Issues in Suicide* 202 (1996), quoting C. Owens et al., *Cancer Patients' Attitudes to Final Events in Life: Wish for Death, Attitudes to Cessation of Treatment, Suicide and Euthanasia*, 3 *Psycho-Oncology* 1 (1994). It is worth emphasizing that the cases before this Court involve what is presently, and is likely to remain, a minority of patients who reach a carefully considered decision to hasten the end of life, even after a thorough exploration of the alternatives.

As mental health professionals, we have no interest in "promoting" assisted suicide. Our interest lies, instead, in the promotion of patient autonomy, balanced by concern for the welfare and protection of the public, and in the sound development of the law to that end.

### CONCLUSION

The judgments of the courts of appeals should be affirmed.

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Dated: December 10, 1996

**APPENDIX A**

**Coalition of Mental Health Professionals  
Supporting Individual Self-Determination in  
Decisions to Hasten Death**



Individuals' affiliations are provided for identification only. The views expressed are those of individual coalition members and not necessarily those of any institution or organization with which they may be affiliated.

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**APPENDIX B**

**National Association of Social Workers  
Policy Statement**

## **Client Self-determination in End-of-Life Decisions**

### **BACKGROUND**

End-of-Life decisions are the choices made by a person with a terminal condition regarding his or her continuing care or treatment options. These options may include aggressive treatment of the medical condition, life-sustaining treatment, palliative care, passive euthanasia, voluntary active euthanasia, or physician-assisted suicide. For the purposes of this policy statement, these terms are defined as follows:

*Terminal and irreversible condition* means a continual profound comatose state with no reasonable chance of recovery or a condition caused by injury, disease, or illness, which, within reasonable medical judgment, would produce death within a short time and for which the application of life-sustaining procedures would serve only to postpone the moment of death. There is no universally accepted definition of "a short time," but in general it is considered to be less than one year (American Hospital Association, 1991).

*Client self-determination* means the right of the client to determine the appropriate level, if any, of medical intervention and the right for clients to change their wishes about their treatment as their condition changes over time or during the course of their illness. Self-determination assumes that the client is mentally competent.

*Incompetent* means lacking the ability, based on reasonable medical judgment, to understand and appreciate the nature and consequences of a treatment decision, including the significant benefits and harms of and reasonable alternatives to any proposed treatment decision.

*Advance health care directive* is a document in which a person either states choices for medical treatment or designates who should make treatment choices if the person should lose decision-making capacity. Although the term "advance directive" generally refers to formal, written documents, it may also include oral statements by the patient (American Hospital Association, 1991).

*Life-sustaining treatment* is medical intervention administered to a patient that prolongs life and delays death (American Hospital Association, 1991).

*Medically inappropriate life-sustaining procedures* means life-sustaining procedures that are not in accord with the patient's wishes or that are medically futile.

*Palliative care* is medical intervention intended to alleviate suffering, discomfort, or dysfunction but not to cure (American Hospital Association, 1991).

*Passive euthanasia* is the withholding or withdrawing of life-sustaining treatment. It is the forgoing of treatment, sometimes called "letting die." The right-to-die rulings such as in the Karen Ann Quinlin case establish the right under certain circumstances to be disconnected from artificial life support.

*Voluntary active euthanasia* is a physician's administering a lethal dose after a clearly competent patient makes a fully voluntary and persistent request for aid in dying. This is the active termination of a patient's life by a physician at the request of the patient.

*Physician-assisted suicide* is a patient's ending his or her life with the means requested of and provided by a physician for that purpose. The physician and the patient are both involved. Nurses or significant others may also be involved, but the physician has the responsibility for

providing the means. In all cases, the patient will have been determined competent to make such a decision.

Some argue that little distinction exists between euthanasia and physician-assisted suicide other than mechanical or technical difference as to who—the patient or the physician—triggers the event. Others (for example, Quill, 1991) maintain the difference is significant in that in assisted suicide the final act is the patient's; the risk of subtle coercion from doctors, family, or other social forces is reduced; the balance of power between patient and physician is more equal; and there is less risk of error, coercion, or abuse.

There has been a proliferation of state legislation related to assisted suicide, including Washington State's "Death with Dignity" initiative, which was narrowly defeated in a referendum in 1991, and bills that were in progress in 1993 in the California, Iowa, Maine, Michigan, and New Hampshire state legislatures. (The Michigan bill required social work counseling to qualified applicants for assisted suicide.) Currently, 37 states outlaw actively helping a patient to die (Brody, 1992).

The Patients' Self-Determination Act of 1990, included in the Omnibus Budget Reconciliation Act of 1990, requires all hospitals participating in Medicare or Medicaid to ask all adult inpatients if they have advance directives, to document their answers, and to provide information on state laws and hospital policies. Other health agencies such as home health and hospice have instituted similar requirements (American Hospital Association, 1991). In many of these facilities, social workers are called on to work with patients regarding advance health care directives and end-of-life decisions.



## ISSUE STATEMENT

Advances in medical capabilities and technology have made it possible to extend life through artificial means that were heretofore unimaginable. Although this level of care often provides enormous benefits for patients, it may also present difficult and increasingly complex ethical choices for patients, their families, and health care professional. Inappropriate or unwanted utilization of medical technology may lead to lessened quality of life, loss of dignity, and loss of integrity of patients.

State and federal legislation related to advance health care directives has raised public awareness about the right of patients to participate in medical decision making, including end-of-life decisions. The individuals most immediately facing end-of-life decisions are those with a terminal and irreversible condition, a progressive chronic illness, or chronic intractable pain.

As advocates for the rights of individuals; as providers of mental health services; and as workers in hospitals, hospices, nursing homes, and crisis centers, social workers regularly deal with quality-of-life issues and choices related to life and death. Social workers have requested guidelines that are compatible with professional and personal ethics, legal parameters, and respect for client self-determination. Furthermore, other professionals look to social work for guidelines on these complex issues:

Social work values, our traditional role as advocates and enablers, and our self-awareness and conscious use of self should serve as justification for engaging people in open and honest debate, recognizing the biases that society and the health care system have had with respect to the backgrounds, lifestyles, and illness of different groups of patients . . . . The

social work community has the opportunity and the obligation to educate, organize, and advocate for a more widespread and extensive debate of these life and death matters. (Mizrahi, 1992)

In acknowledging and affirming social work's commitment to respect diverse value systems in a pluralistic society, end-of-life issues are recognized as controversial because they reflect the varied value systems of different groups. Consequently, the National Association of Social Workers (NASW) does not take a position concerning the morality of end-of-life decisions, but affirms the right of the individual to determine the level of his or her care.

It is also recognized that de facto rationing of health care based on socioeconomic status, color, ability to pay, provider biases, and government policy differentially affects people's right to choose among viable service alternatives and their ability to give truly informed consent. The social worker should work to minimize the effect of these factors in determining the care options available to individuals:

In examining the social work role in working with clients around end-of-life decisions, the following issues must be addressed:

- the legal parameters that affect social work practice (for example, limits of confidentiality, state laws prohibiting assisted suicide, the potential for civil liability)
- the potential conflict of social work values with those of other health care professionals
- the emerging pressures for cost control and rationing of healthcare (for example, temptation of health care institutions and insurers to encourage use of end-of-life practices to control costs)

- the possibility of patients feeling obliged to choose death rather than becoming a burden (Brock, 1992)
- the societal limits on individual self-determination and autonomy
- the necessity to define safeguards to protect individual and society in the implementation of end-of-life practices

#### POLICY STATEMENT

NASW's position concerning end-of-life decisions is based on the principle of client self-determination. Choice should be intrinsic to all aspects of life and death.

The social work profession strives to enhance the quality of life; to encourage the exploration of life options; and to advocate for access to options, including providing all information to make appropriate choices.

Social workers have an important role in helping individuals identify the end-of-life options available to them. This role must be performed with full knowledge of and compliance with the law and in accordance with the *NASW Code of Ethics* (NASW, 1993). Social workers should be well informed about living wills, durable power of attorney for health care, and legislation related to advance health care directives.

A key value for social workers is client self-determination. Competent individuals should have the opportunity to make their own choices but only after being informed of all options and consequences. Choices should be made without coercion. Therefore, the appropriate role for social workers is to help patients express their thoughts and feelings, to facilitate exploration of alternatives, to provide information to make an informed choice, and to deal with grief and loss issues.

Social workers should not promote any particular means to end one's life but should be open to full discussion of the issues and care options. As a client is considering his or her choices the social worker should explore and help ameliorate any factors such as pain, depression, need for medical treatment, and so forth. Further, the social worker should thoroughly review all available options including, but not limited to, pain management, counseling, hospice, nursing home placement, and advance health care directives.

Social workers should act as liaisons with other health care professionals and help the patient and family communicate concerns and attitudes to the health care team to bring about the most responsible assistance possible.

Because end-of-life decisions have familial and social consequences, social workers should encourage the involvement of significant others, family, and friends in these decisions. Social workers should provide ongoing support and be liaisons to families and support persons (for example, caregivers, significant others) with care to maintain the patient's confidentiality. When death occurs, social workers have an obligation to provide emotional and tangible assistance to the significant others, family, and friends in the bereavement process.

Social workers should be free to participate or not participate in assisted-suicide matters or other discussions concerning end-of-life decisions depending on their own beliefs, attitudes, and value systems. If a social worker is unable to help with decisions about assisted suicide or other end-of-life choices, he or she has a professional obligation to refer patients and their families to competent professionals who are available to address end-of-life issues.

It is inappropriate for social workers to deliver, supply, or personally participate in the commission of an act

of assisted suicide when acting in their professional role. Doing so may subject the social worker to criminal charges. If legally permissible, it is not inappropriate for a social worker to be present during an assisted suicide if the client requests the social worker's presence. The involvement of social workers in the assisted suicide cases should not depend on race or ethnicity, religion, age, gender, economic factors, sexual orientation, or disability.

NASW chapters should facilitate their membership's participation in local, state, and national committees, activities, and task forces concerning client self-determination and end-of-life decision. Education and research on these complex topics should be included in the social work role.

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